Inflammatory Bowel Disease Diagnosis: Factors Influencing Treatment Preferences in Steroid Resistant Ulcerative Colitis – A Qualitative Interview Study

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Background The best treatment option for people whose ulcerative colitis (UC) is resistant to steroids is not clear. Importantly, understanding of patient preferences for available treatments in this setting is also limited. Therefore, the objective of this study was to explore patient experiences of different treatment options, their approaches to decision making, and preferences for available treatments for steroid resistant UC.

Results 114 diagnoses of IBD were made during the study period, of which 60 were via 2ww referral (52.6%). 52.6% were male, with a median age of 45.0 years. 76 patients were diagnosed with ulcerative colitis (UC, 66.7%), 34 with Crohn’s disease (CD, 29.8%), and four with IBD unclassified (IBDU, 3.5%). Patients referred on the 2ww pathway were significantly older than those diagnosed via routine GP referral (figure 1a, median age 45.0 vs. 30.5 years, p<0.0001). Treatment was commenced earlier for patients referred on the 2ww pathway than those referred routinely (figure 1b, median 2.9 vs. 13.2 weeks, p<0.0001). This was accounted for exclusively by the longer time between referral and colonoscopy in the standard vs. the 2ww cohorts (median 10.6 vs. 2.0 weeks). Time from referral to treatment initiation was greater for patients diagnosed with CD than those diagnosed with UC (median 10.4 vs. 5.0 weeks, p<0.0001). Of patients referred on a 2ww pathway, 85.0% commenced treatment within 18 weeks of referral, compared to 61.1% of those referred routinely.

Conclusions Most IBD diagnoses were made following 2ww pathway referral. Despite uncertainty about whether this would permit access to the most appropriate specialist, patients on the 2ww pathway had a shorter referral to treatment time than those referred routinely due to access to earlier diagnostic colonoscopy. The longer wait for treatment in Crohn’s disease may reflect a reluctance or difficulty in starting steroids or immunomodulators in this cohort. A substantial proportion of patients referred on both pathways are not being treated within the recommended 18 week window.
Methods Qualitative interview study with adults living with UC recruited from three Inflammatory Bowel Disease (IBD) services in the North of England, undertaken between 4th June and 31st October 2019. Data were collected during telephone interviews, digitally recorded and transcribed. Inductive thematic analysis was performed by two researchers using NVivo software. Codes were cross-checked and data saturation was confirmed prior to study close.

Results A total of 33 adults participated (51% female, median age 39 years, median time since diagnosis 6 years). Thematic saturation was confirmed. Four key themes were identified in the data. (1) Treatment effectiveness: this was the primary concern of all participants when choosing a new treatment. Participants explained that alleviating symptoms improving quality of life was the most important driver of their treatment preferences. (2) Influence of healthcare professionals: treatment discussions and choices were heavily guided by IBD healthcare professionals (HCPs). Most participants in this study described the valuable relationships that they have within IBD nurses and medics, and how they trust and respect their clinical expertise. (3) Other influences: whilst important to treatment choices, participants placed limited value on the route of administration and side effects relative to treatment effectiveness overall. (4) Changes over time: there was an increased willingness to try alternative treatments, and eventually surgery over time, in accordance with the severity and duration of symptoms, and crucially, as medical treatment options are exhausted.

Conclusion The importance of treatment efficacy and the influential role of HCPs when patients choose treatments for steroid resistant UC has been highlighted – with a willingness to consider different treatments over time. Less value was placed on side-effects and route of administration. This study provides a qualitative perspective on patient preferences which should be considered in practice guidelines and trial design.

P97 MANAGEMENT OF STEROID RESISTANT ULCERATIVE COLITIS – A NATIONAL SURVEY OF UK PRACTICE

Introduction Corticosteroids are a mainstay in the treatment of moderately severe relapses of ulcerative colitis (UC), yet almost 50% of patients do not respond fully, with the risk of prolonged steroid use and side-effects. There is insufficient evidence to inform optimum treatment choice for steroid resistant disease. The aim of this study was to provide details of current practice in the management of steroid resistant UC.

Methods A cross-sectional survey of Inflammatory Bowel Disease (IBD) healthcare professionals (HCPs) in the UK was conducted online using the Qualtrics platform. HCPs were invited to participate in the survey through professional networks: British Society of Gastroenterology IBD section, Royal College of Nursing IBD Nurses Network, and social media. Clinical scenarios representing patients with moderately severe UC with continuing symptoms (steroid resistant (SR)) and with relapse after steroid dose reduction (steroid dependent (SD)) were included – both thiopurine treated (TP+) and naïve (TP-). Data were analysed descriptively with chi-squared tests on outcomes of interest using R software.

Results 387 HCPs visited the survey; 47% (168 HCPs) consented (68% medical; 30% nurses; median 7.5 years since appointment) across all UK regions. Definitions of steroid resistance varied: 68% indicating an incomplete response to prednisolone 40 mg/day after 2 weeks and after 4 weeks in a further 58%. Only 13% felt that SR and SD disease should be treated identically.

Anti-TNF drugs would be most frequently offered in each scenario (SR: TP+ 95%; TP- 87%; SD: TP+ 88%; TP- 74%) with infliximab most frequently suggested; apart from SD TP-patients flaring at prednisolone 5 mg/day. Admission for IV steroids was offered more often for SR disease (32%) than for SD (12%).

In SD scenarios, thiopurine treatment would be instigated in TP- patients flaring at 25 mg prednisolone or 5 mg/day in 49% and in 70% respectively. Anti-TNF treatment would be offered more frequently if patients are TP+ in both SR (TP+ 81%; TP- 62% p=0.004) or SD patients and particularly for those relapsing at 5 mg/day (Relapse at 25 mg/day: TP+ 78% TP- 49%, p<0.001; Relapse at 5 mg/day TP+85% TP- 46%, p<0.001). For both SR and SD disease, 43% and 58% respectively felt that endoscopy is not warranted.

Conclusions There are important variations in practice in the UK in how to define, treat and use endoscopy in steroid resistant UC. Such variations need to be understood as part of initiatives to change practice - particularly to avoid excess steroid use - and in trial design.

P98 DISEASE INVOLVEMENT IS COMMON AMONG PAEDIATRIC CROHN’S DISEASE PATIENTS: A STUDY FROM THE BIOLOGIC ERA

Introduction Paediatric Crohn’s disease (PCD) often presents with a pan-enteric phenotype at diagnosis. However, its long-term evolution in to adulthood, especially since the advent of biological therapy, is not well characterised. Only few studies have assessed this change, with conflicting results and limited by short follow-up times. Our study aimed to evaluate how the PCD phenotype evolves through childhood into adult life.

Methods We performed a single-centre retrospective study of PCD patients diagnosed ≤16 years of age, transitioned to an adult gastroenterology unit with a minimum follow up of 2 years. Disease location and behaviour was characterised using Paris and Montreal classification at diagnosis and follow-up respectively. We assessed for evidence of disease extension or involvement as well as variables associated with complicated disease behaviour and surgery. Comparison of frequencies was performed using Pearson’s chi-square test. Hazard ratios from Cox proportional hazards models were used to quantify risk of surgery and complicated disease behaviour.

Results 132 patients were included, transitioning to adult care between 2002 and 2016. The median age at diagnosis was 13 (IQR 11–14) and median follow up 11 years. At diagnosis, 27